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No.95-1858

IN THE
SUPREME COURT OF THE UNITED STATES

October Term, 1995

DENNIS C. VACCO, et al.,
Petitioners,
v.
TIMOTHY E. QUILL, et al.,
Respondents.

ON WRIT OF CERTIORARI TO THE UNITED
STATES COURT OF APPEALS FOR THE
SECOND CIRCUIT

**BRIEF AMICI CURIAE OF
NOT DEAD YET and AMERICAN DISABLED FOR
ATTENDANT PROGRAMS TODAY IN SUPPORT OF
PETITIONERS**

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AMICI CURIAE BRIEF OF
NOT DEAD YET and AMERICAN DISABLED FOR
ATTENDANT PROGRAMS TODAY IN SUPPORT OF
PETITIONERS

INTERESTS OF AMICI CURIAE

Amici are two national organizations composed primarily of persons with disabilities, including persons with spina bifida, cerebral palsy, muscular dystrophy, spinal cord injuries, multiple sclerosis, quadriplegia, paraplegia, head and brain injuries, polio, amyotrophic lateral sclerosis, as well as many other disabilities. Most of these

persons use assistive devices, including motorized and manual wheelchairs, ventilators, and personal assistance services for meeting their personal hygiene needs, transferring from bed to wheelchair and preparing food.

NOT DEAD YET is a national organization of people with severe disabilities who oppose the legalization of assisted suicide because it singles out people with significant health impairments for assistance to die, denying them the equal protection of laws and medical practice standards automatically applied to healthy individuals who are suicidal. Since 1985, individuals who are now Not Dead Yet members have participated actively in numerous states in the formulation of public policy concerning the so-called "right to die," have written numerous published articles on the issue, and were invited and testified recently before the Constitution Subcommittee of the Judiciary Committee of the U.S. House of Representatives on assisted suicide.

AMERICAN DISABLED FOR ATTENDANT PROGRAMS TODAY (ADAPT) is a national organization, most of whose members have severe disabilities and have been institutionalized in nursing facilities and other public institutions solely because they have disabilities. ADAPT has a long history and record of enforcing the civil rights of people with disabilities and was one of the key organizations

that participated in the political and legislative process that resulted in the passage in 1990 of the Americans With Disabilities Act, 42 U.S.C. § 12101 et seq., ("ADA"). It was the plaintiff in the case ADAPT v. Skinner, U.S. Department of Transportation, 867 F.2d 1471, 881 F.2d 1184 (3d Cir. 1989).¹

SUMMARY OF ARGUMENT

Discrimination against people with severe disabilities pervades our society. Assisted suicide is the most lethal form of such discrimination. Applied only to people with significant health impairments, assisted suicide is the ultimate expression of society's fear and revulsion regarding disability. Health status becomes the basis of a double standard in which people with disabilities, a "discrete and insular minority," 42 U.S.C. § 12101(a)(7), are discriminatorily denied the protection of suicide prevention laws, medical practice standards, and statutes prohibiting abuse, neglect and homicide that nondisabled persons receive. This double standard based on health status violates the ADA.

Given the pervasive prejudice against and social devaluation of people with severe disabilities and the absence of adequate health

¹ All parties have consented in writing to filing of this brief. Copies of the written consents are on file with the Clerk of the Supreme Court.

care and appropriate supportive services, safeguards cannot be established to prevent abuses resulting in the wrongful death of numerous disabled persons, old and young.

If, however, this Court were to uphold a constitutional right to assisted suicide or authorize its legalization by states, such provisions should apply to everyone -- regardless of health status or disability -- on a nondiscriminatory basis.

ARGUMENT

I. The Creation Of A Right To Assisted Suicide For A Class Of Individuals Based On Health Status Or Disability Is A Lethal Form Of Discrimination Which Violates The ADA.

A. People With Disabilities, With Either Terminal Or Nonterminal Health Impairments, Are The Class Of People Affected By The Proposed Right To Assisted Suicide.

The outcome of this case potentially threatens the lives and well-being of a significant number of the 23,588,000 noninstitutionalized people in the United States who have severe disabilities.² They comprise 12.1 percent of the total population, 15 years old and over in the United States. The outcome will also affect the only minority group, people with disabilities, that is open to all regardless of race, gender, nationality, sexual orientation, income, place

² U.S. Dep't. of Commerce, Statistical Abstract of the United States 1994 at 137 (114th ed. 1994)(Table No. 202). Census data is not available for people with severe disabilities who are institutionalized.

of residency, political affiliation, or any other characteristic, and the only minority group, from a statistical viewpoint, which only 9 percent of its members join at birth.

There are five primary bases for asserting that people with severe disabilities, including nonterminal disabilities, are the actual and potential victims of a right to assisted suicide:

1. Courts in numerous jurisdictions have ruled that people with severe but nonterminal disabilities may legally be denied suicide prevention that nondisabled people routinely receive, but are to be treated like terminally ill people, with respect to the withholding and withdrawal of life sustaining medical treatment.³

2. The diagnosis and prognosis of terminal illness is inherently uncertain, as respondents themselves admit.⁴ In addition, many doctors conclude that lives of people with severe disabilities are not worth saving, solely because of their disabilities. The potential for error and abuse against people with severe disabilities is too great.

3. Over three quarters of Jack Kevorkian's assisted suicides involved people who were clearly not terminally ill under

³ See *infra* at 7-10.

⁴ Timothy Quill, et al, Sounding Board: Care of the Hopelessly Ill, *New Eng. J. of Med.* 1380, 1381, Nov. 5, 1992.

accepted medical definitions, but were only severely disabled.⁵

4. In the Netherlands, a country in which assisted suicide has been widely accepted and practiced for many years and the country often referred to as "the model" for the United States, a governmental report demonstrates that many people with nonterminal disabilities have been killed, and thousands have been killed involuntarily.⁶

5. Well-known proponents of assisted suicide have written that it should be applied to people with nonterminal disabilities.

In Final Exit, Hemlock Society founder Derek Humphry writes,

What can those of us who sympathize with a justified suicide by a handicapped person do to help? When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases.

Many cases in which state courts have expanded the right to refuse treatment demonstrate that prejudice, stereotypes and devaluation of people with disabilities have already had a substantial

⁵ See Appendix A or a list of Kevorkian's "patients" by age, diagnosis and health status at the date of death.

⁶ Paul J. van der Maas, et al., Euthanasia and Other Medical Decisions Concerning the End of Life, 338 Lancet 669, 672 (1991).

adverse impact on members of this minority group. Flagrant prejudice against people with disabilities pervades each decision.

Elizabeth Bouvia wanted medical support while starving herself to death. She had blamed herself for her parents' divorce. When she was ten her mother placed her in an institution, visiting her only twice in eight years. At eighteen, she moved to her own apartment, earned a college degree and began working on a master's degree. She had a series of emotional blows, including a miscarriage, the death of her brother, serious financial distress, withdrawal from graduate school because of discrimination, and separation from her new husband.⁷ A nondisabled person with this history, who refused nutrition and requested physician assistance to commit suicide, would have been diagnosed as suicidal and provided suicide intervention and treatment. But because Ms. Bouvia also had cerebral palsy, a lifelong, nonterminal disability, it was concluded that her decision to die was reasonable and not deserving of intervention.⁸ However, only following two years of

⁷ See L. Hearn, It's More of a Struggle to Live than Die, Chi. Trib. Feb. 8, 1984, Sec. 51-53; Robert A. Bernstein, Accept the Disabled, N.Y. Times, Jan. 10, 1984, at A23; David Gelman & Daniel Pedersen, The Most Painful Question, Newsweek, Jan. 16, 1984, at 72; Paul K. Longmore, Elizabeth Bouvia, Assisted Suicide and Social Prejudice, 3 Issues in Law & Med. 141, 153 (1987).

⁸ Much to the dismay of members of the disability community, including amici, death row prisoners receive more suicide prevention than Ms. Bouvia, Mr. Bergstedt and other persons with severe disabilities. See e.g., Autry v. McKaskle, 727 F.2d 358 (5th Cir. 1984).

lengthy court proceedings did Ms. Bouvia decide not to exercise her newly won right.

Kenneth Bergstedt had quadriplegia and used a ventilator. Throughout his 30 years of life, Mr. Bergstedt was dependent on his father, who, fearing he would soon die of lung cancer, supported his son's decision to die. A psychiatric report before a lower court declared Mr. Bergstedt to be depressed but presumed this was due to "the quality of life for this man...." ⁹ Mr. Bergstedt believed that he would be forced to live in a nursing home after his father's death and was unaware of in-home service alternatives. The Nevada Supreme Court pointed out that Mr. Bergstedt's

suffering resulted more from his fear of the unknown than any source of physical pain.... It is equally clear that if Kenneth had enjoyed sound physical health, but had viewed life as unbearably miserable because of his mental state, his liberty interest would provide no basis for asserting a right to terminate his own life with or without the assistance of others. ¹⁰

Ruling after his death, even the Nevada Supreme Court, which had supported Mr. Bergstedt's request for physician assisted suicide, recognized that he had not been properly informed and had not made

⁹ McKay v. Bergstedt, 801 P.2d 617, 637 (Nev. 1990) (dissent observing that "[w]ith this kind of support it is no wonder that he decided to do himself in").

¹⁰ Id. at 624-25 (emphasis added).

a free and intelligent life-or-death decision. If he were still alive, the court said "it would have been necessary to fully inform him of the care alternatives that would have been available to him after his father's death or incapacity." ¹¹

David Rivlin was paralyzed as a result of a surfing accident a full eighteen years before he committed suicide with the aid of medical support. He had no terminal illness, but he used a ventilator. He was confined to a nursing home in Michigan against his will because of the lack of adequate in-home support services at that time. In addition, his relationship with his fiancé had recently ended. ¹² Mr. Rivlin was given his "right to die" but was never offered the options he expressly requested to live in the community.

Larry McAfee, a thirty-four year old man with quadriplegia as a result of an accident, was transferred from one institution to another "like a sack of potatoes" over a period of four years. ¹³ Georgia did not pay for community support but would pay only for the

¹¹ Id. at 628. Presumably, these care alternatives included the personal assistance that millions of other people with severe disabilities receive and with which they live in the community.

¹² Stanley S. Herr, et al., No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities, 8 Issues in Law & Med. 3, 13-15 (1992).

¹³ Peter Applebome, An Angry Man Fights to Die. Then Tests Life, N.Y. Times, Feb. 7, 1990, at A 1.

cost of nursing home care¹⁴ and for intensive care in a hospital unit where he lived for eight months, even though he was not ill, let alone critically or terminally ill.¹⁵ The Georgia Supreme Court affirmed the lower court's assessment that Mr. McAfee was hopelessly injured.¹⁶ In the nursing home, he was told when to eat, sleep, and even what he could watch on his own video recorder.¹⁷ Nevertheless, after disability rights advocates including members of the amici communicated with Mr. McAfee, he changed his mind. By the time Mr. McAfee won his so-called "right to die," he had worked with disability advocates to get out of the nursing home and pursue work as an engineer using computer aided drafting. Mr. McAfee had experienced how people with severe disabilities are devalued as human beings and was quoted as saying,

You're looked upon as a second-rate citizen. People say, 'you're using my taxes. You don't deserve to be here. You should hurry up and leave.' You reach a point where you just can't take it anymore.¹⁸

¹⁴ See also, Helen L. v. DiDario, 46 F.3d 325 (3d Cir.1995) cert. denied, 116 S.Ct. 64 (1995) sub nom. Secretary of DPW of Pa. v. Idell S.

¹⁵ Steven A. Holmes, Disabled People Say Home Care Is Needed to Use New Rights, N.Y. Times, Oct. 14, 1990, at Sec.1.2.

¹⁶ State v. McAfee, 259 Ga. 579, 385 S.E.2d 651,652 (Ga. 1989).

¹⁷ Joseph Shapiro, Larry McAfee, Invisible Man: The Agonizing Fight to Prevent Legalized 'Suicide', U.S. News & World Rep., Feb.19, 1990, at 59, 60.

¹⁸ Id. at 60

These four cases are examples of discrimination against and devaluation of people with disabilities. These decisions occurred because the general public, including judges and physicians, share common societal reactions to people with severe disabilities:

1. nondisabled persons fear that they will become disabled themselves and assume that having a severe disability is worse than death itself;

2. nondisabled persons often view people with severe disabilities as lacking in "quality of life," and such people are to be pitied instead of being granted civil rights or equal legal protections; and

3. to many nondisabled persons, disability falsely implies entrapment, loss of control, and loss of dignity.

As a consequence of these reactions, persons with severe disabilities are segregated, put out of sight in institutions, or neglected, abandoned, abused, and increasingly assisted to die. These public misconceptions, however, are refuted by research studies on disabled people's quality of life.¹⁹

Each of these cases dismissed the state interest in protecting

¹⁹ See e.g., J.R.Bach & M.C.Tilton, Life Satisfaction and Well Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia, 75 Arch. of Physical Med. & Rehab. 626 (1994).

the lives of these disabled individuals and found a "right to die" through the withdrawal of life-sustaining treatment. However, the courts specifically distinguished any right involving active physician-assisted suicide. Before this Court is the request to obliterate this distinction.

Reviewing the people whom Jack Kevorkian assisted in committing suicide also demonstrates the potential for uncontrolled discrimination against people with disabilities, if this Court sanctions active physician-assisted suicide. Of the 40 people who died between June 4, 1990 and September 7, 1996 with the assistance of Kevorkian, at least 28 people had diseases that were not life-threatening and autopsies revealed they were not terminally ill.²⁰ For example, nine of them had multiple sclerosis. As the New York Times recently reported in connection with these people,

multiple sclerosis is not a fatal disease.... Its tendency to wax and wane repeatedly and unpredictably can have patients wavering back and forth between elation and despair.... [T]he depression that often accompanies the disease is a treatable condition.... [S]ervices are available to help every person with illness live a more productive and comfortable life and that whatever the state of a person's disability, life need not be worthless.²¹

²⁰ Thomas Maier, Waiting at Death's Door, Newsday, Sept. 8, 1996, at A 4-5. See Appendix A.

²¹ Jane E. Brody, Putting Emphasis on Assisted Living with M.S., N.Y. Times, October 23, 1996 at C 11.

Like those people who had multiple sclerosis, most of Kevorkian's other "patients" did not have terminal illnesses nor did they receive appropriate services to help make life meaningful. For example, **Janet Adkins**, age 54, who died June 4, 1990, was in the early stages of Alzheimer's, was not terminally ill, and her own doctor said she had ten years of productive life ahead of her. She never met or spoke with Kevorkian until two days before her death. According to an aunt, "She did not want to be a burden to her husband and family."²² **Marjorie Wantz**, age 58, who died October 23, 1991, had no life-threatening condition, had reportedly experienced pelvic pain, but an autopsy found she had no apparent illness or disease.²³ **Sherry Miller**, 42, who died October 23, 1991, had multiple sclerosis and could have lived for many years but felt she was "becoming a burden on people," and she had suffered from depression but did not want to take the medication for it.²⁴ **Elaine Goldbaum** had financial problems and

²² Georgea Kovanis, Profession Condemns Doctor, Detroit Free Press, June 7, 1990 at 1A; Doctor Ordered Not to Use Suicide Device, San Francisco Chronicle, June 9, 1990 at A 1; Stuart Wasserman, What Drove Woman to Suicide Machine, San Francisco Chronicle, June 7, 1990 at A 2.

²³ James A. McClear, Murder Charges for Dr. Death?, Detroit News, Dec. 19, 1991 at 1A.

²⁴ Id.

feared losing her house,²⁵ Jonathan Grenz was said to be depressed and "overwhelmed with grief" following his mother's death,²⁶ and Ali Khalili had told his doctor that "the quality of his life had been compromised by an anxiety state."²⁷ Kevorkian assisted them all to die.

These people represent the extent of discrimination that exists in our society; with appropriate treatment and services, many of them would be alive today. It is against the backdrop of these and other cases, reflecting society's growing support of a "right to die" for people with severe disabilities, that your amici request protection from the very real threat to the lives of people with disabilities that will result from a right to assisted suicide through active measures.

B. Denying People With Disabilities The State Benefit Of Suicide Prevention And Enforcement Of Abuse, Neglect And Homicide Laws Violates The ADA.

Lethal discrimination against people with severe disabilities and functional limitations is an integral and pervasive part of America's twentieth century history. The forms of this lethal discrimination include:

²⁵ Robert Ourlian & Mike Martindale, Kevorkian Assists in 12th Suicide, Detroit News, Feb. 9, 1993 at 1B,6B.

²⁶ Carol J. Castaneda & Robert Davis, Kevorkian: Death Must Be An Option, USA Today, Feb. 22, 1994, at 1A, 2A.

²⁷ Don Terry, While Out on Bail, Kevorkian Attends a Doctor's Suicide, N.Y. Times, Nov. 23, 1993 at A 1,B 9.

1. euthanasia, where nondisabled persons advocated for the involuntary euthanasia of 60,000 disabled persons in institutions and five times as many outside, since in these "hopeless" cases "we have no fear of error";²⁸

2. eugenics "favoring the killing of defective children;"²⁹

3. involuntary sterilization of persons with developmental and physical disabilities;³⁰

4. denial of life-saving medical assistance especially to

²⁸ F.Kennedy, The Problem of Social Control of the Congenital Defective, 99 Am. J. Psych. 13-16 (1942). See also, The Right to Kill, Time, Nov. 18, 1935, at 53-54 (where a Nobel Prize winner at the Rockefeller Institute urged that "sentimental prejudice... not obstruct the quiet and painless disposition of incurable... and hopeless lunatics"); D. McKim, Heredity and Human Progress 189,193 (1900)(where a respected New York physician advocated the elimination of all severely handicapped children, including "idiots," most "imbeciles, and the greater number of epileptics, for society's protection, via a "gentle, painless death" by the inhalation of carbonic gas).

²⁹ D.B. Shurtlett, Myelodysplasia: Management and Treatment, 10 Current Problems in Pediatrics 1, 8 (1980). See Nat Hentoff, Are Handicapped Infants Worth Saving? Village Voice, Jan 8, 1991, at 18; Richard J. Neuhaus, The Return of Eugenics, Commentary, Apr. 1988, at 15-26.

³⁰ Although the Court recognized the historical practice of "putting away ... the offspring of the inferior, or of the better when they chance to be deformed" [would] do violence to both the letter and spirit of the Constitution," Meyer v. Nebraska, 262 U.S. 390, 401-02 (1923), three years later it upheld the constitutionality of sterilization imposed by a State because Carrie Buck was labelled "feeble-mindedness." Buck v. Bell, Superintendent of the Virginia Colony for Epileptics and Feeble Minded, 274 U.S. 200, 207 (1927). Buck ratified the view of the feeble-minded as "a menace," holding: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." Id.

children with severe physical disabilities;³¹ and

5. withdrawal of medical treatment.³²

This Court has acknowledged that at least one of the forms of this discrimination, the practice of withholding lifesaving medical assistance by medical professionals from children with lifelong severe disabilities, has a "history of unfair and often grotesque mistreatment" arising from a legacy of "prejudice and ignorance" and continuing well into the 20th century. City of Cleburne, Texas v. Cleburne Living Center, 105 S. Ct. 3249, 3262 (Stevens, J., joined by Burger, C.J., concurring), 3266 (Marshall, joined by Brennan & Blackmun, JJ., concurring)(1985).

Congress clearly understood this history when, in 1990, it enacted the ADA, the basic civil rights statute for people with disabilities. After extensive hearings, Congress made extensive

³¹ Studies reveal that many physicians, a majority in some specialties, oppose lifesaving surgery for babies with lifelong disabilities. A. Shaw, et al., Ethical Issues in Pediatric Surgery, 60 Pediatrics 588, 590 (1977); R.H. Gross, et al., Early Management and Decision-Making for the Treatment of Myelomeningocele, 72 Pediatrics 450, 456 (1983) (reporting on the results of selection of handicapped newborns for treatment between 1977 and 1982 at Oklahoma University Health Sciences Center that babies were provided - or denied - treatment based on such factors as their ambulatory potential, according to a "formula that also factored in the "contribution anticipated from his home and family and society"); D. Crane, The Sanctity of Social Life at 96-98 (1975) (documenting that surgeons at a teaching hospital were actually less likely to perform surgery on Down syndrome children with heart defects than survey studies would predict).

³² See e.g., Elizabeth Bouvia, Kenneth Bergstedt, David Rivlin and Larry McAfee, supra at 7-10.

Findings:

historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination continue to be a serious and pervasive social problem;

unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;

individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion..., segregation, and relegation to lesser ... benefits...;

census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged...;

individuals with disabilities are a discrete and insular minority..., subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to society; and

the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity ... to pursue those opportunities for which our free society is justifiably famous.

42 U.S.C. §§12101(a)(2),(4)-(7) and (9)(emphases added).

To address and remedy this pervasive and relentless discrimination, Congress substantively required that "no qualified individual with a disability shall, by reason of such disability, be

excluded from participation in or be denied the benefits of the services, programs, or activities of any public entity...." 42 U.S.C. § 12132. The same prohibition applies to hospitals and physicians. 42 U.S.C. § 12182(b)(2)(A)(iii). Elizabeth Bouvia, Kenneth Bergstedt, Janet Adkins, Marjorie Wantz, Sherry Miller and the other people discussed above had disabilities (or were perceived to have disabilities) and all of them, "by reasons of [their] disability," were denied the state's benefits of suicide prevention and/or enforcement of abuse, neglect, and homicide statutes. The states concluded that their fundamental interests in saving lives applied only to people without severe disabilities.

Pursuant to the ADA's explicit statutory mandate, 42 U.S.C. § 12134, the U.S. Department of Justice promulgated federal regulations elaborating on the statutory definition of discrimination. Specifically, the regulations provide that a state, as well as hospitals and doctors, discriminate when they either deny or do not afford an opportunity for people with disabilities to benefit from services either equal to or as effective as that afforded nondisabled persons. See e.g., 28 C.F.R. § 35.130(b).

Providing assisted suicide only for people with severe disabilities and conversely denying suicide prevention services only for people with severe disabilities violates the ADA in at least four

respects:

1. The presence or absence of a severe disability determines whether state and local governments enforce laws requiring health professionals to protect individuals who pose a danger to themselves. The disability, instead of the risk of suicide, determines the enforcement.

2. The presence or absence of a severe disability determines whether the state and medical practitioners respond to expressions of suicidal intent in people with disabilities with the application of lethal measures that are never applied to people without disabilities. The existence of a severe disability will be the reason for the denial of treatment that nondisabled persons routinely receive. Society's growing support of such discrimination is founded on inaccurate assumptions about the needs of persons with incurable health conditions, the role and authority of physicians, and the nature and significance of requests to die as they are understood and valued by physicians.³³

3. The presence or absence of a severe disability determines whether state and local governments investigate or enforce potential medical malpractice, such as failure to provide pain medication, failure

³³ The clinical aspects of such discrimination are explained in Appendix B, excerpts of Affidavit of Carol Gill, Ph.D. from the record in Lee v. Oregon, 869 F. Supp. 1491 (Ore.D., 1994)

to establish an accurate diagnosis, prognosis and treatment plan, and failure to ensure informed consent. If one has a severe disability, each of these are treated differently than if one were nondisabled, resulting in a double standard that depends only on the existence of a severe disability.

4. The presence or absence of severe disability determines whether and the extent to which state and local governments investigate and enforce abuse and neglect and homicide statutes in cases reported as assisted suicides. Amici's experiences demonstrate that noninvestigation and nonenforcement are common practices when it comes to the death of people with disabilities.³⁴

The existence of a disability should never be the basis for these distinctions.

³⁴ There are already documented cases of discriminatory enforcement of homicide statutes. **Myrna Lebov**, a woman with nonterminal multiple sclerosis, was pressured and assisted to die by her husband, Mr. Delury who stated that he had repeatedly told his wife that she was a terrible burden on him, telling her that she was "a vampire sucking [his] life away." Herbert Hendin, Dying of Resentment, N.Y. Times, March 21, 1996 (Op-Ed Page). Mr. Delury plead guilty to a charge of attempted manslaughter and was sentenced to only 6 months in prison.

A mother recently killed her brain injured non-verbal teenage daughter. The judge said her actions were understandable, and other parents could be expected to react in the same way. She was sentenced to community service. B. Harris, Mom Freed in Mercy Killing, Spokesman-Review, Jan. 10, 1996 at A1, A7.

II. Adequate Safeguards Cannot Be Adopted To Protect People With Disabilities From Assisted Suicide Abuse And Therefore An Unequivocal Rule Must Be Established Prohibiting Assisted Suicide.

A. Any Purported Limitation Of The Right To Assisted Suicide To Terminally Ill Persons Will Not Protect People With Severe Disabilities.

Given the "history of purposeful unequal treatment" to which people with disabilities are subjected and the "continuing existence of unfair ... discrimination and prejudice," 42 U.S.C. § 12101 (a)(7) & (9), adequate assisted-suicide safeguards cannot and will not prevent abuse against people with disabilities. History, contemporary attitudes and biases, the Netherlands, as well as prior judicial decisions, demonstrate that safeguards against abuse in assisted suicide cannot be developed. Amici discussed the current practices which demonstrate that assisted suicide has not and will not be limited to terminally ill persons.³⁵ As long as society, including the medical profession, demonstrates ignorance and prejudice regarding the lives of people with disabilities, no safeguards can be trusted to contain the torrent of discrimination that will be unleashed by lifting the ban on assisted suicide.

At issue in the present case is nondisabled peoples' intense fear of becoming disabled. When a person with a disability states a

³⁵ See *infra* at 7 -10.

desire to die, nondisabled people believe the request is natural and reasonable because they believe that living with a severe disability is a life of dependency, indignity and helplessness; in short, worse than death. The wish to die agrees with the nondisabled view that the primary problem for disabled people is the permanent disability and/or dependence on life aids. Medical professionals, jurists and the public consistently ignore underlying treatable depression, lack of health care or other supports, and exhaustion from confronting systemic discrimination. When medical professionals and the media use phrases like "imprisoned by her body," "helpless," "suffering needlessly," and "quality versus quantity of life," purportedly in a humanistic and compassionate way, they are really expressing very primitive human fears of severe disability and a very misguided condemnation, "I could never live like that." Society translates these primitive emotions into a supposedly rational social policy of assisted suicide. Whenever

permanent disability is [defined] as the problem, death is the solution.... [T]he wish to die is transformed into a desire for freedom, not suicide. If it is suicide at all, it is 'rational' and, thereby, different from suicides resulting from [the same] emotional disturbance or illogical despair [that nondisabled persons face].³⁶

³⁶ C.J.Gill, Suicide Intervention for People With Disabilities: A Lesson in Inequality, 8 Issues in Law & Med. 37, 39 (1992).

The medical profession is not immune to these erroneous assumptions. Research shows that doctors frequently project the "quality of life of chronically ill persons to be poorer than patients themselves hold it to be, and give this conclusion great weight in inferring, incorrectly, that such persons would choose to forgo life-prolonging treatment."³⁷ It is particularly important to note that research on suicidal feelings among people with terminal illnesses demonstrates that such feelings are remediable through other means, including pain management, hospice services and counselling.³⁸ As long as physicians believe that a person with a severe disability has a "life unworthy of living,"³⁹ lethal errors and abuses will occur.

³⁷ S. Miles, Physicians and Their Patients' Suicides, 271 J.A.M.A. 1786 (1994).

³⁸ Most death requests, even in terminally ill people are propelled by despair and treatable depression. Herbert Hendin and Gerald Klerman, Physician-Assisted Suicide: The Dangers of Legalization, 150 Am. J. of Psych. 143 (Jan. 1993).

³⁹ It was in Germany in the 1930s, preceding the well-known holocaust of Jewish people, that the Nazis instituted a program to eliminate approximately 200,000 persons with physical and mental disabilities because their lives were "unworthy of living." See e.g., H. Gallagher, By Trust Betrayed (1990); R. Proctor, Racial Hygiene - Medicine Under the Nazis (1988); R. Lifton, The Nazi Doctors - Medical Killing and the Psychology of Genocide (1986) (the medical profession was not coerced but were willing initiators); G.Aly, The Legalization of Mercy Killings in Medical and Nursing Institutions in Nazi Germany from 1938 Until 1941, Int. J. of Law And Psychiatry 145 (1984). The same attitude recently pervaded China's policies in the killing of children with disabilities. Human Rights Watch/Asia, Death by Default - A Policy of Fatal Neglect in China's State Orphanages (1996).

B. Any Purported Limitation Of A Right To Assisted Suicide Only In Cases Of "Voluntary" Requests Will Not Protect People With Disabilities From Abuse.

As long as people with disabilities are treated as unwelcome and costly burdens on society, assisted suicide is not voluntary but is a forced "choice." Amici are profoundly disturbed by the finding of a constitutional right for assisted suicide in a society which refuses to find a right to adequate and appropriate health care to stay alive. Until society is committed to providing life supports, including in-home personal assistance services, health care, and technological supports, then there is not voluntary choice.

Our nation's health care system has not responded adequately or consistently to the health needs of people with disabilities. Now managed health care, with its emphasis on cost containment and the inevitable denial of health care, will further abridge the choices and endanger the lives of people with disabilities.

Without access to competent medical care, options and information about disability, people with severe disabilities are not able to make informed decisions. Without the professional commitment to help make living worthwhile for people with disabilities, which is the core of suicide prevention, people with disabilities will not receive the support necessary for informed and voluntary decisions.

Additionally, there is substantial evidence that physicians and other health care providers will engage in euthanasia in the absence of a patient's clear request to die, and even in opposition to a clear request to live:

1. Recent medical studies indicate that involuntary "do not resuscitate" ("DNR") orders are not uncommon.⁴⁰ Many members of your amici have been repeatedly requested and pressured to sign DNR requests. Maria Matzik, a Not Dead Yet and ADAPT member and a 34 year old ventilator user, was told by health care professionals in a hospital that a DNR order would apply to her because she uses a ventilator, despite her express demand to the contrary.

2. Cases have been brought by health care professionals seeking authority to withhold treatment in opposition to express patient and family directives to the contrary.⁴¹

3. Evidence from the Netherlands demonstrates quite unequivocally that involuntary euthanasia has become widespread and frequent, even with established written safeguards in place. Specifically, according to a 1990 governmental report, 5,941 persons

⁴⁰ D. Wassel & R. Truog, The Cardiopulmonary Resuscitation Order - Not - Indicated Order: Futility Revisited, 122 Ann. of Int. Med. 304 (1995).

⁴¹ E. Walsh, Spouse Says He'd Never Agree to Cut Life Support, Wash. Post, May 30, 1991, Sec. A at 3.

were given lethal injections without their consent. Of those, 1,474 were fully competent, according to their physicians. In 8% of the cases, doctors admitted there were unexplored options. Regardless of options, they euthanized unconsenting patients because of such express reasons as "low quality of life," "no prospect of improvement," "and "the family could not take any more."⁴² There is no reason to believe that safeguards will work any better in the United States. To the contrary, once assisting disabled people to their deaths becomes routine in medical training and practice, no safeguards are possible behind the closed doctors' doors to protect people with disabilities against well-intentioned, but lethal prejudice exhibited by many physicians.

4. If a right to assisted suicide is created, then, as existing court precedent and state statutes involving refusal of treatment indicate, such a "right" will soon be extended in practice to incompetent persons through the use of advanced directives and surrogate decision-makers. Research shows that families are likely to believe that assisted suicide is a desirable option, and that a disabled family member would want assisted suicide, even though that family member in fact does not

⁴² Richard Fenigsen, *Euthanasia: The Medicine and Fear*, Doctor Assisted Suicide and the Euthanasia Movement, G. McCuen, ed. at 76, 80 (1994); see also Maas, *supra* at n. 6.

want aid in dying.⁴³ Amici contend that a right to assisted suicide for competent adults will increase the danger of lethal decisions by families, whether well-intentional or otherwise.

5. The history of discrimination against persons with disabilities in health care settings, coupled with current developments in managed care, demonstrates that assisted suicide is the easiest and most financially profitable way to address the needs of persons with disabilities. With assisted suicide, a doctor under a capitated health care system will not have to exceed his utilization rate on a severely disabled patient. There are no safeguards that can protect against these prejudices and realities.

Finally, no system of safeguards can control conduct which results in the death of the primary witness to any wrongdoing or duress. The only "safeguard" that offers some protection against abuse is that assisted suicide remain illegal and socially condemned for all citizens equally. As assisted suicide becomes more and more acceptable, the threat of criminal prosecution is the only remaining protection to which people with severe disabilities, including terminal illnesses, can turn. For example, 16% of nurses report engaging in the practices,

⁴³ H.G. Koenig, et al., *Attitudes of Elderly Patients and Their Families Toward Physician-Assisted Suicide*, 156 Arch. of Int. Med., 2240 (1996).

sometimes without the consent of the patient.⁴⁴ In the absence of any potential for criminal liability, no meaningful barrier to active involuntary euthanasia will exist to protect the lives of members of this minority group.

III. If This Court Finds That Either A Constitutional Or Statutory Right To Assisted Suicide Exists, Then This Right Should Be Afforded To Everyone Without Discriminating Against People Because Of Health Or Disability Status.

The proposed right to assisted suicide discriminates, singling out people with severe disabilities as fit to die. Since this discrimination is so pervasive in our society, amici urge that if any right to obtain assistance to control one's death exists, it should apply to everyone in a nondiscriminatory manner and not be limited to persons with severe disabilities, including terminal illnesses.

If the Constitution requires that the state's interest in the preservation of life (through suicide prevention and other laws) is vitiated for some people because of their health status, then why should the state interest not also be discounted for other persons? Why should one's autonomy or right to control one's death be limited to persons with severe disabilities? Why exclude from this right persons enduring extreme, unabating psychological suffering due to the irreversible loss

of loved ones? There is no constitutional basis for drawing a bright line on a continuum between disabled and nondisabled. Such a distinction would stand on shifting sands of arbitrary classifications and assessments, as well as changing medical and technological expertise and developments.

Moreover, if proponents of assisted suicide believe that adequate safeguards against treatable suicidal feelings can be established, then they should be willing to allow physician assistance for every citizen, regardless of their health status, after those safeguards have been observed.

Amici ask the Court to believe them when they state that disability-based discrimination in this culture is deep-seated, virtually unconscious, pervasive and overwhelming. This discrimination against millions of Americans must be understood and reversed, in ways that few can even envision, long before we discuss expanding the ways in which society's unwanted can be killed. But if physician-assisted suicide will become a right for some, then it should be for all. The same safeguards, or lack of safeguards, that apply to some must apply to all, without discrimination.

⁴⁴ D. A. Asch, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 334 N. Eng. J. of Med., 1374 (1996).

CONCLUSION

The circuit courts' conclusions that people with disabilities are not threatened by physician-assisted suicide is false, based on virtually every court decision to date, as well as on the actual practice in our society. The fact that proponents of assisted suicide continue to dismiss and marginalize the input of the disability rights community on this topic leads amici to believe that they may actually feel that their untimely deaths are ultimately acceptable in the interest of the "greater good," or even only in the interest of their individual need to maintain control in an uncertain and often cruel world.

People with disabilities request this Court protects their lives, to stand as perhaps the last barrier to the "right to die" juggernaut of the recent decade, to recognize that cloaked in the false rhetoric of "personal autonomy," physician assisted suicide threatens the remaining rights of a profoundly oppressed and marginalized people.

Respectfully submitted,

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APPENDIX A

The following people were Kevorkin's "patients" through September 7, 1966:¹

NAME, AGE, DATE DIED, STATUS AND CONDITION AT TIME OF DEATH

JANET AKINS, 54, 6/4/90. Not Terminal. Had Alzheimer's disease.
SHERRY MILLER, 43, 10/23/91. Not Terminal. Had multiple sclerosis with disorganization of motor control in legs and arms.
MARJORIE WANTZ, 58, 10/23/91. Not terminal. Had severe pelvic pain.
SUSAN WILLIAMS, 52, 5/15/92. Not terminal. Had multiple sclerosis and was blind.
LOIS HAWES, 52, 9/26/92. Terminal stages of lung cancer.
CATHERINE ANDREYEV, 46, 11/23/92. Terminal stages of breast cancer.
MARCELLA LAWRENCE, 67, 12/15/92. Not terminal. Had heart disease, emphysema and arthritis.
MARGUERITE TATE, 70, 12/15/92. Terminal stages of Lou Gehrig's disease.
JACK MILLER, 53, 1/20/93. Terminal stages of bone cancer. Also had emphysema.
STANLEY BALL, 82, 2/4/93. Not terminal. Had pancreatic cancer.
MARY BIERNAT, 73, 2/4/93. Had breast and chest cancer. Unclear whether terminal.
ELAINE GOLDBAUM, 47, 2/8/93. Not terminal. Had multiple sclerosis, was blind and use a wheelchair.
HUGH GALE, 70, 2/15/93. Unclear whether terminal. Had emphysema and congestive heart disease.
JONATHAN GRENZ, 44, 2/18/93. Terminal. Had throat cancer.

¹ Thomas A. Maier, Waiting at Death's Door, Newsday, September 8, 1996 at A40, A51, & A53.

MARTHA RUWART, 41, 2/18/93. Terminal. Had duodenal and ovarian cancer.

RON MANSUR, 54, 5/16/93. Unclear whether terminal. Had lung and bone cancer.

THOMAS HYDE, 30, 8/4/93. Terminal. Had Lou Gehrig's disease.

DONALD O'KEEFE, 73, 9/9/93. Terminal. Had bone cancer.

MERIAN FREDERICK, 72, 10/22/93. Not terminal stage of Lou Gehrig's disease.

ALI KHALILI, 61, 11/22/93. Not terminal. Had progressive bone disease and multiple myeloma.

MARGARET GARRISH, 72, 11/26/94. Not terminal. Had double amputation from chronic degenerative joint disease.

JOHN EVANS, 77, 5/8/95. Not terminal. Had chronic lung disease.

NICHOLAS LOVING, 27, 5/12/95. Not terminal stage of Lou Gehrig's disease.

ERIKA GARCELLANO, 60, 6/26/95. Not terminal stage of Lou Gehrig's disease.

ESTHER COHAN, 46, 8/25/95. Not terminal. Had multiple sclerosis.

PATRICIA CASHMAN, 58, 11/8/95. Not terminal. Had breast cancer.

LINDA HENSLEE, 48, 1/29/96. Not terminal. Had multiple sclerosis.

AUSTIN BASTABLE, 53, 5/6/96. Not terminal. Had multiple sclerosis.

RUTH NEUMAN, 69, 6/10/96. Not terminal. Was overweight and had diabetes.

LONA JONES, 58, 6/18/96. Not terminal. Had a brain tumor.

BETTE LOU HAMILTON, 67, 6/20/96. Not terminal. Had a degenerative neurological disease.

SHIRLEY CLINE, 63, 7/4/96. Not terminal. Had colon cancer.

REBECCA BADGER, 39, 7/9/96. Not terminal. Had multiple sclerosis.

ELIZABETH MER CZ, 59, 8/6/96. Not terminal. Had Lou Gehrig's disease.

JUDITH CURREN, 42, 8/15/96. Not terminal. Had chronic

fatigue syndrome and muscle disorder.

DORTHA SIEBENS, 76, 8/20/96. Not terminal. Had Lou Gehrig's disease.

PATRICIA SMITH, 40, 8/22/96. Not terminal. Had multiple sclerosis.

PAT DIGANGL, 66, 8/22/96. Not Terminal. Had debilitating muscle illness.

JACK LEATHERMAN, 73, 9/2/96. Terminal. Had pancreatic cancer.

ISABEL CORREA, 60, 9/7/96. Not terminal. Had severe pain from a spinal cord condition.

APPENDIX B

Excerpts from Affidavit of Carol Gill, Ph.D. in record in Lee v. Oregon, 869 F. Supp. 1491 (Ore. D. 1994).

I am a clinical psychologist specializing in issues affecting persons with disabilities, pain, and/or chronic illnesses. . . My former positions include: Director of Rehabilitation Psychology at Glendale Adventist Center; Commissioner in Psychology on the Los Angeles County Commission on Disability ; and Acting Director of the Program in Disability and Society at the University of Southern California . . . In addition . . . I have been physically disabled since contracting polio in childhood and relying on a power wheelchair for mobility and a ventilator for respiration during the night . . .

I have observed that a primary source of depression and despair in clients with disabilities and chronic progressive illnesses is their demoralization by social discrimination in daily life. After struggling with employment bias, unaccommodating and selective health services, lack of accessible and affordable housing, and lack of accessible transportation, many of my clients and research subjects have expressed feelings of severe emotional exhaustion commonly referred to as "burn-out." In fact, the most frequently repeated theme from persons with disabilities and illnesses that I have encountered in the last decade has been, "I can live with my physical condition but I'm tired of struggling against the way I'm treated."

In the case of spinal cord injury, for example . . . [it] is quite common for persons who first learn of their paralysis and are confronted with assistive technology and unfamiliar procedures to express the desire to die; and to express it forcefully and consistently for weeks. Months later, however, most of those patients thank their doctors and families for supporting their lives instead of concluding with their earlier despair

[W]hen the "critical life stress" involves a life-threatening illness or disability, the process of adjustment often takes considerably longer. Therapists experienced in working with terminally ill and irreversibly disabled individuals report a series of stages - including shock, grief, despair, and resolution - that are navigated before such individuals regain basic emotional control However, emotional disorder can well be hidden and remain undetected unless carefully assessed by properly trained professionals. Most physicians are not trained to identify hidden depression, treatable suicidal intent, and other non-flagrant psychiatric disorders. Studies have revealed that a significant portion of persons who attempt suicide seek medical attention shortly before the event and that their physicians typically remain unaware of their emotional distress and need for psychological intervention Attending physicians, therefore, have not proven to be qualified gatekeepers in determining a patient's need for psychological services.

In my clinical practice and in my subsequent education and research contacts, I have heard repeated complaints from persons with incurable health conditions that their physicians are often unaware of their needs, devaluing their lifestyles, and uninformed about such important options as personal in-home assistance, independent living centers, and assistive technology. These complaints are confirmed by research For example, research reveals that health professionals often prejudge the lives of ventilator-users as poor in quality. These negative judgments are not only at odds with the generally high life satisfaction ratings of ventilator-users themselves, but are also associated with a lack of knowledge about options for assisted ventilation and a tendency to withhold such options from patients Those of us who have worked extensively with suicidal persons realize

that the wish to die can sound unwavering and can persist for many weeks and yet be characterized by deep ambivalence. The presence of a terminal illness or even substantial physical suffering does not in any way diminish the possibility of significant conflict between the wish to die and the desire to live.

It is extremely dangerous to respond to the expression of a death wish by providing the means to die. That type of response, especially if it comes from a respected authority or representative of society (e.g., a physician), can unduly influence a vulnerable individual to embrace death as the "right" solution

For example, the desire to die may result from the previously mentioned exhaustion after a struggle to live in the face of thwarting social barriers and discrimination. Self-destructive impulses may also represent an internalization of the stigma and devaluation society inflicts on persons with incurable conditions - an internalization of the pervasive message that physical weakness is "undignified" but that dying is "humane and dignified." Suicide may be a desperate attempt to control one's life when the surrounding environment is dismissive of one's needs or unwilling to support alternative ways to enhance self-determination, e.g., assistive technology and dignified personal assistance in one's own home. Embracing death may be a tragic effort to escape the imprisonment of a nursing home or other intolerable institutional setting. It may be an attempt to ward off impending abandonment or rejection from others who cannot cope with a loved one's physical decline. It may be a self-sacrificing measure to spare family members from the financial strain that often accompanies lingering illness in our society. The expression of a desire to die may be a poignant way of testing the waters to see if others feel it is time for the ill individual to get out of the way. These are all socially mediated reasons for wanting to die. They should be addressed through modifying the social environment, not accepting the individual's self-elimination.

The expressed desire to escape illness by dying can also be a sign of treatable clinical depression, anxiety disorder, or other mental illness. Researchers who studied terminally ill people seeking a

hastened death found that most, in fact, had a psychiatric disorder Preoccupation with physical discomfort and the tendency to express emotional distress in somatic complaints is a common symptom of clinical depression. We cannot assume that simply because a person is physically ill, he or she is immune from the treatable psychiatric problems that visit many physically healthy persons have. . . . Not all persons with incurable conditions enjoy the middle-class ideal of the stable doctor-patient relationship. Many are impoverished and see a series of doctors who are assigned to them. They may opt for death because they cannot afford many of the comforts and options available to others. If they qualify for a lethal prescription, it is likely to come from a stranger who knows little about them instead of the trusted family physician envisioned by many of the more privileged . . .

In light of the disturbing facts presented above, I submit that the Oregon death with Dignity Act singles out a class of persons that society has already too quick to discard and further reduces support for and protections of their lives That bias is an insidious form of prejudice that disability rights activists call "ableism" or "physicalism." A society that weighs the value of a citizen's life according to health or physical attributes is entering risky territory. When physicians are instructed to adopt such a scale with impunity, the silent and far-reaching effects on health care and on society as a whole will be as impossible to predict as to control. One of the most certain and tragic outcomes, however, is that it will lead to the wrongful premature deaths of persons who, if given basic support and reasonable options instead of a socially and medically sanctioned exit, would prefer to live.